

## Living Well in West Memphis on October 30, 2003

If you live in eastern Arkansas, mark your calendars for October 30, 2003, and plan to be in West Memphis. The Arkansas Spinal Cord Commission (ASCC) is hosting an educational conference, *Living Well with Spinal Cord Injury*, on October 30, 2003, from 9:00 a.m. to 4:00 p.m. at the MidSouth Community College in West Memphis.

In keeping with the wellness theme of the conference, sessions will include physical activity and nutri-

tion for people with spinal cord disabilities, sessions on local resources including independent living and water exercise, maintaining a healthy outlook and a medical session on the latest research in spinal cord injury. In addition, regional exhibitors will provide information and demonstration of the latest assistive technology and medical equipment and supplies.

Lunch is complimentary and door prizes will be awarded at the end of the day! Registration fee is \$10 for

ASCC clients and families and \$20 for health care and other professionals. Scholarships are available for clients and families.

Come hear the latest on living well with spinal cord disabilities. For additional information or to register for the conference, call Pam Young at **870-735-4725**.

## Peter DeFrancisco – Expert Woodworker

From a distance, the steam engine (*see photo below*) looks a lot like those plastic kit models you buy at the hobby store. You know, the ones that come with an instruction sheet and a zillion mass-produced plastic parts you glue together. But, upon closer inspection, you realize that this is no ordinary scale model.



Peter DeFrancisco of Russellville presents his hand-carved steam engine to ASCC Client Services Administrator Patti Rogers.

For this is a model made by Peter DeFrancisco, expert woodworker.

Peter's models first impress you with the detail—from the lights on the front to the rivets on the boiler. Second, you noticed that everything is made out of wood—hand-carved wood. And thirdly, things that are supposed to move actually move. Not only do the wheels move left and right and around the axle but the hydraulic pistons also move back and forth. And the track on the bulldozer moves!

Now how did Peter get those hand-carved track pieces to link together and move at the same time, without falling off?

Some of Peter's competitors would like to know because several of his models have won blue ribbons and "Best of Show" at the county fair. This year he plans to enter his

latest model, a road grader/earth scraper (*see photo, page 3*), and it looks like the model to beat.

Peter was always interested in woodworking but it wasn't until his grandsons, Matthew and Chris,

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## SPINAL COURIER

Published quarterly by  
Arkansas Spinal Cord Commission

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**[www.state.ar.us/ascc/](http://www.state.ar.us/ascc/)**  
or e-mail us at:  
**[courier@arspinalcord.org](mailto:courier@arspinalcord.org)**

## With Thanks

*Donations this quarter from:*

**Leona Estes**  
**Fellowship Baptist Church**  
**of Batesville**  
**Esther Karp**

*In Honor of Donald Hughes:*  
**Jewell Hughes**

*In Memory of Jack L. Thomas:*  
**Donna and John Wyrick**

ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission**  
**1501 N. University, Suite 470**  
**Little Rock, AR 72207**

## SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

### *From the Director*

By now, most of you have heard of HIPAA. Not the two-ton water animal, though it may feel like that's what it is to some of us, but the ***Health Insurance Portability and Accountability Act of 1996, Public Law 104-191***. This law, the last remnant of the health care reform initiatives of the 1990s, was designed to provide us with better access to our health care benefits and to protect the privacy of our health information. Sounds good doesn't it? It is! The portability part has been in place for several years and has benefited many people, especially those with disabilities who want to change jobs without losing their health insurance.

The accountability part, known as the Privacy Rule, just went into effect this year. The **HIPAA Privacy Rule regulates how health care providers may use and share your health care information**. It prevents your protected health information (PHI) from being used without your knowledge and approval for anything other than treatment, payment or health organization (internal agency processes). What does this mean? For example, it means that your insurance provider cannot sell your name and address to companies who market medical supplies and equipment. It means your doctor or hospital cannot give out information to anyone about your condition without your approval, except to obtain treatment for you. It also means that you can get copies of your health information from providers and can request that they change it if there is misinformation in the record (though they are not required to do so unless the error can be confirmed).

This is where that two-ton water animal comes in. In order to carry out HIPAA, health care agencies have been required to make a lot of changes in the way they do things. You may have noticed that things have changed when you go for health care. You are required to sign a HIPAA Privacy notice at every office, you don't sign in on a list any more, friends and family may even have trouble finding out if you are in the hospital. These are small prices to pay for privacy.

ASCC is a "covered entity" according to HIPAA regulations. We keep a limited amount of health care information about our clients in order to assist them in obtaining needed care and services. For the most part, how ASCC manages your health information has not changed. We have always been careful about protecting your information. We do not give or obtain health information about you without your permission, unless it is to provide a service you have requested (e.g., providing necessary medical information to a provider to purchase you a cushion or wheelchair). Confidentiality has been and will always be a tenet of the services ASCC provides. However, now we will be adding some procedures to stay in compliance with HIPAA. One of those is the **ASCC Privacy Notice** printed on **pages 5 and 6** of this newsletter. This notice provides you with information about how ASCC manages your protected health information and how you can access it, or make a complaint if you think it has been misused. We hope you will keep this notice for future reference.

You will likely be hearing more about HIPAA over the next months and years. I urge you to ask questions if you have them. I can assure you, ASCC will continue to make every effort to maintain your privacy while providing you the best services we can! Count on it!

Enjoy the wonderful colors of the Arkansas autumn!

*Cheryl L. Vines*

# Spina Bifida Camp 2003

This summer, Camp Aldersgate was the place to be! Forty young campers with spinal cord disabilities attended the Spina Bifida Camp June 22 to June 27.

Each year the campers are divided into two teams or tribes—the Caddo and Quapaw. As always, there was fierce competition between the two tribes. All week long these two teams competed in various activities to earn points.



*Camper Patrice Marshall and Counselor Katie Beaton enjoy the pool.*

These activities included nature hikes, outdoor cooking, arts and crafts, swimming, fishing, drama and music, accessible adventure/challenge ropes course, hand and/or foot driven catamarans, adapted archery, and for older campers, scuba diving.



*Campers Jesus Miranda-Martinez, Garrett Ramsfield and Tia Ramsfield and Counselor Donald Betzold pause for a quick photo.*



*Keagan Allen is glad he came to camp!*



*Dominique Briggs is ready for the fun to begin!*

On Friday morning, family members and staff filled the Matkin building to capacity for the awards ceremony. Excitement grew as the campers piled into the auditorium.

Each camper received an award. Patrice Marshall of Warren was awarded the Joe Morgan Super Camper award. At last the final tally was done, and the winning tribe was announced. This year's winner was the Quapaw tribe.



*Campers Hannah Loomis, Julie Carpenter, Heather Bowers and Krystal Carter and Volunteers Miesha Buckner and Riley Thomas are having a great time!*

Spina Bifida Camp is a collaborative program supported by the Arkansas Spinal Cord Commission, Camp Aldersgate and MedCamps of Arkansas.

If you missed Camp this year, and want to participate next year, **be sure to look for details in our January 2004 newsletter or talk with your ASCC Case Manager.**

## Peter DeFrancisco

Continued from page 1



*This hand-carved bulldozer has wooden tracks that actually move!*

persuaded him to make them some toy trucks that he really became "hooked" on woodworking and modeling. His first few attempts were a little crude but with the encouragement of his wife, Virginia, he quickly became adept at making the little parts that make a true-to-life scale model.

Diagnosed with Guillain-Barré in 1979 at the age of 47, Peter became unable to work as a machinist when the disease left him with peripheral neuropathy, weak legs and back. He now uses a wheelchair and crutches for very short distances. His experience as a machinist has given him an eye for detail and precision that he applies to his woodworking. Sometimes, when he has trouble sleeping, he will "perfect" in his mind his latest design. When the daylight comes, he's back in the shop putting his ideas into creation.

Woodworking helps Peter exercise his mind and hands and keeps him going and connected to his family and the community. His wife, children and grandchildren have been blessed with furniture, doodads,

treasure chests and toys. And through the Russellville Woodworkers Club, Peter has made Christmas toys for area children and birdhouses for Camp Aldersgate in Little Rock.

Woodworking is Peter's way of sharing his talents with others and his next project is eagerly anticipated.



*This road grader/earth scraper is Peter DeFrancisco's latest model.*

# Parastep® System

By Tom Kiser, M.D., ASCC Medical Director



Every patient I work with in clinic and at the hospital is interested in walking and wants to know what the medical field and research is doing to help them realize their goal. The Parastep® system is an old system that has been given new life and may help us take steps (no pun intended) toward that goal. It is a system that has been available since 1994, but was approved for coverage by Medicare on April 1, 2003.

The Parastep® system is a device that uses neuromuscular electrical stimulation to stimulate the intact nerves in a person with a spinal cord injury. To be specific, it uses electricity to cause contraction of the Gluteal (in the buttocks) muscles to extend the hips, the Quadriceps (in the front of the thigh) muscles to extend the knee, and stimulates the Peroneal nerve (that pulls your ankle up) to pick up the leg. **This allows the person to stand and take steps with a walker.**

To qualify for the system you have to **meet certain criteria:**

1. Have intact lower motor nerves to the legs (if you have spasticity in the legs this is a good sign that the nerves are intact)
2. Have good trunk balance and stable joints in the arms and legs (can transfer independently and stand with the device independently for at least 3 minutes)
3. Have brisk muscle contraction when electrical stimulation is applied to the nerves of the muscles
4. Be at least six months out from the spinal cord injury
5. Have adequate hand and finger function to manipulate the control switches

6. Have no hip or knee arthritis or history of leg fractures

You will **not** qualify for the system if you have:

1. Severe scoliosis (curvature of the back) or osteoporosis (weak bones)
2. Severe contractures in the legs
3. A pacemaker or heart defibrillator
4. Skin disease on the legs where the electrodes need to be placed
5. Inability to tolerate the intensity of the electrical stimulation due to sensation or autonomic dysreflexia

As for those who qualify, they will **need to commit to a rigorous training program of at least 32 sessions of physical therapy over a three-month period** to learn to use the system effectively. Some individuals will require lower extremity bracing with an in-the-shoe ankle brace to stabilize the ankle.

The benefits that have been shown in research studies are:

1. Increases in muscle mass in the thigh and calf
2. Improved cardiovascular fitness
3. An improvement in self-esteem and a decrease in symptoms of depression

There was no benefit found in improving bone density in the hip region.

To be successful with the Parastep® system **a person must be highly motivated and willing to work hard in therapy.** The person who will benefit the most from this system is the one who would like to use it for an exercise program, and to stand and walk short distances.

Muscle fatigue in the stimulated

muscles is still a big problem with neuromuscular stimulation and is hard to overcome.

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## Spina Bifida Association of Arkansas Announces Scholarship Awards

The Spina Bifida Association of Arkansas (SBAA) announced their 2003 scholarship awards in September. The recipients of these \$500 scholarships are both ASCC clients. James Rucker of Scott, AR is pursuing his doctorate in biochemistry at Louisiana State University. Deborah Oyler of Fox, AR, a 2003 high school graduate, will attend Ozarka College in Melbourne and pursue training in Medical Transcription. ASCC members and staff offer our hearty congratulations to both Deborah and James as they pursue their careers! If you have spina bifida and are a high school senior or college student and are interested in applying for a SBAA scholarship, contact the Association at **501-978-7222** for an application.

The Corvette Club of Arkansas has served as a benefactor and supporter of the programs of SBAA for over 15 years. Each year, the Club donates proceeds of their annual car show to SBAA to support programs including scholarships, family support, recreation opportunities and information packets for families of new babies with spina bifida. This year the Corvette Club made an \$8,000 contribution to the Association.

For more information, or if you would like to join the SBAA, call **501-978-7222**.



## Arkansas Spinal Cord Commission

Effective Date: April 14, 2003

### NOTICE OF PRIVACY PRACTICES FOR INDIVIDUALS SERVED

**THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.**

**PLEASE REVIEW IT CAREFULLY!**

We are required to provide you with this *Notice of Privacy Practices* and to explain our legal duties under the federal Health Insurance Portability and Accountability Act (HIPAA).

We are required by law to maintain the privacy of medical information about you. We call this information “protected health information” or PHI. We are required to give you notice of our privacy practices about your protected health information and required to follow the terms of the notice currently in effect.

This Notice of Privacy Practices will tell you how we may use or disclose information about you. Not all situations will be described.

In the future we may change the Notice of Privacy Practices. Any changes will apply to information we already have and any information we receive in the future. A copy of the new notice will be posted at each ASCC facility and provided to individuals as required by law. You may request a copy of the current notice at any time by contacting ASCC.

#### **WE MAY USE AND DISCLOSE PHI ABOUT YOU WITHOUT YOUR AUTHORIZATION**

**For Treatment:** We may use or disclose PHI about you with health care providers who are involved in your health care. For example, information may be shared to make an appointment or referral for evaluation or treatment.

**For Payment:** We may use or disclose PHI about you to get payment or to pay for health care services you receive. For example, we may provide PHI to order medical equipment or supplies.

**For Health Care Operations:** We may use or disclose PHI information about you in order to manage our programs and activities. For example, we may use PHI about you to review the quality of services you receive.

#### **OTHER WAYS WE MIGHT USE OR DISCLOSE PHI ABOUT YOU WITHOUT YOUR AUTHORIZATION**

**Appointments and Other Health Information:** We may send you reminders for medical care or checkups. We may send you information about health services that may be of interest to you.

**For Health Oversight Activities:** We may use or disclose PHI about you to inspect or investigate health care providers.

**As Required By Law and For Law Enforcement:** We will use and disclose PHI about you when required or permitted by federal or state law or by a court order.

**For Abuse Reports and Investigations:** We are required by law to report any allegations of child abuse or neglect.

**For Government Programs:** We may use or disclose PHI about you for public benefits under other government programs. For example, we may disclose information for determination of Supplemental Security Income (SSI) benefits.

**To Avoid Harm:** We may disclose PHI about you to law enforcement in order to avoid a serious threat to the health and safety of a person or the public.

**For Research:** We may use PHI about you for studies and to develop reports. These reports do not identify specific people.

#### **WE MAY USE AND DISCLOSE PHI ABOUT YOU WITHOUT YOUR AUTHORIZATION UNLESS YOU OBJECT**

**Disclosure:** We may disclose PHI about you to your guardian, interdisciplinary team members, or other persons who are involved in your medical care.

#### **OTHER USES AND DISCLOSURES REQUIRE YOUR WRITTEN AUTHORIZATION**

**For Other Situations:** We will ask for your written authorization before using or disclosing PHI about you. You may cancel this authorization at any time in writing, or by other appropriate means of communication if necessary. We cannot take back any uses or disclosures already made with your authorization.

*(Continued on page 6 - See ASCC Privacy Notice)*

## ASCC Privacy Notice

Continued from page 5

### **YOUR PHI PRIVACY RIGHTS**

**Right to See and Get Copies of Your PHI:** In most cases, you have the right to look at or get copies of your PHI. You must make the request in writing. You may be charged a fee for the cost of copying and mailing the PHI to you.

**Right to Request to Correct or Update Your PHI:** You may ask us to change or add missing PHI if you think there is a mistake. You must make the request in writing and provide a reason for your request. However, there are conditions under which we may deny this request.

**Right to Get a List of Disclosures:** You have the right to ask us for a list of disclosures made after April 14, 2003, and up to six years prior to the date you made the request. You must make the request in writing. This list will not include the times that PHI about you was disclosed for treatment, payment, or health care operations. This list will not include PHI about you provided directly to you or your family, or PHI that you authorized.

**Right to Request Limits on Uses or Disclosures of Your PHI:** You have the right to ask us to limit how PHI about you is used or disclosed. You must make the request in writing and tell us what PHI you want to limit and to whom you want the limits to apply. We are not required to agree to the restriction. You can request that the restrictions be terminated in writing or verbally.

**Right to Revoke Permission:** If you are asked to sign an authorization to use or disclose PHI about you, you can cancel that authorization at any time. You must make the request in writing. This will not affect PHI that has already been shared.

**Right to Choose How We Communicate With You:** You have the right to ask us to share your PHI with you in a certain way or in a certain place. For example, you may ask us to send PHI about you to your work address instead of your home address. You must make this request in writing. You do not have to explain the basis for your request.

**Right to File a Complaint:** You have the right to file a complaint if you do not agree with how we have used or disclosed PHI about you.

**Right to Get a Paper Copy of this Notice:** You have the right to ask for a paper copy of this notice at any time.

### **CONTACT US TO REVIEW, CORRECT, OR LIMIT YOUR PHI**

You may contact us to:

1. Ask to look at or copy your PHI.
2. Ask to limit how PHI about you is used or disclosed.
3. Ask to cancel your authorization.
4. Ask to correct or change PHI about you.
5. Ask for a list of disclosures of your PHI.

We may deny your request to look at, copy, or change your PHI. If we do deny your request, we will send you a letter that tells you why your request is being denied and how you can ask for a review of the denial. You will also receive information about how to file a complaint.

### **HOW TO CONTACT US**

Arkansas Spinal Cord Commission  
Central Office  
1501 N. University, Suite 470  
Little Rock, AR 72207-5233

Cheryl L. Vines, Executive Director  
Voice Phone: (501) 296-1788  
Toll Free: (800) 459-1517  
TDD: (501) 296-1794  
Fax: (501) 296-1787  
[cvines@arspinalcord.org](mailto:cvines@arspinalcord.org)

Patti Rogers, Client Services Administrator  
Voice Phone: (501) 296-1788  
Toll Free: (800) 459-1517  
TDD: (501) 296-1794  
Fax: (501) 296-1787  
[progers@arspinalcord.org](mailto:progers@arspinalcord.org)

### **HOW TO FILE A COMPLAINT OR REPORT A PROBLEM**

You may contact those listed above if you want to file a complaint or to report a problem with how we have used or disclosed your PHI. **Your services will not be affected by any complaints you make.** We cannot retaliate against you for filing a complaint, cooperating in an investigation, or refusing to agree to something that you believe to be unlawful.

You may also file a complaint with the U.S. Department of Health and Human Services, Office of Civil Rights by contacting:

Region VIII, Office of Civil Rights  
Department of Health and Human Services  
1961 Stout Street – Room 1185 FOB  
Denver, CO 80294-3538  
Voice Phone: (303) 844-2024  
TDD: (303) 844-3439  
Fax: (303) 844-2025

# Wheelchair Basketball 2003-04

## Junior Rollin' Razorbacks

Oct. 18-19	Southwest Conference Tournament	Tulsa, OK
Nov. 14-16	HOME – Southwest Conference Tournament & Prep Regional	Hot Springs, AR
Jan. 2-4	Texas Regional Tournament	Dallas, TX
Feb. 14-15	HOME – Southwest Conference Championships	Hot Springs, AR
Mar. 12-14	National Junior Invitational Championships	Baltimore, MD
Mar. 19-21	Prep National Championships	Peoria, IL
Mar. 25-28	National Junior Wheelchair Championships	Philadelphia, PA

*For additional information about joining the Junior Rollin' Razorbacks or their game schedule, please contact Coach Doug Garner at 501-525-4503.*

## Rollin' Razorbacks Schedule

Oct. 4-5	Arkansas Valley Conference Tournament	Muskogee, OK
Nov. 22	Arkansas Valley Tournament	Norman, OK
Dec. 5-7	New Orleans Invitational	New Orleans, LA
Dec. 13	Arkansas Valley Tournament	Ft. Smith, AR
Jan. 10	HOME – Arkansas Valley Tournament	Sherwood, AR
Jan. 15-17	Pioneer Classic	Birmingham, AL
Jan. 25	Dallas Invitational	Dallas, TX
Feb. 7	Arkansas Valley tournament	Muskogee, OK
Feb. 21-22	HOME – Rollin Razorback Invitational	Sherwood, AR
Feb. 28	Arkansas Valley Conference Championship	TBA
Mar. 20-21	NWBA Midwest Regional	TBA
Apr. 2-3	National Wheelchair Basketball Tournament	Phoenix, AZ

*For additional information about joining the Rollin' Razorbacks or their game schedule, please contact Coach Jared Johnson at 501-866-0987.*

## Fort Smith Shooting Stars

Oct. 4-5	Arkansas Valley Conference Tournament	Muskogee, OK
Nov. 22	Arkansas Valley Tournament	Norman, OK
Dec. 13	HOME – Arkansas Valley Tournament	Ft. Smith, AR
Jan. 10	Arkansas Valley Tournament	Sherwood, AR
Feb. 7	Arkansas Valley Tournament	Muskogee, OK
Feb. 28	Arkansas Valley Conference Championship	TBA
Mar. 20-21	NWBA Midwest Regional	TBA
Apr. 2-3	National Wheelchair Basketball Tournament	Phoenix, AZ

*For additional information about joining the Ft. Smith Shooting Stars or their game schedule, please contact Doug Moore at 479-474-0825.*

## Disabled Hunting and Fishing License

The Arkansas Game & Fish Commission (AG&F) has announced a new Resident 3-Year Disability Combination License (\$35.50) for 100 percent disabled persons.

If you wish to purchase a license, bring (a) **proof of one year's residency in Arkansas** (e.g., driver's

license, state ID, property assessments or Arkansas income tax forms) and (b) **acceptable proof of disability** (certification will be accepted from Social Security, Veteran's Affairs or Railroad Retirement).

Applications and information are

available by calling **1-800-364-4263** or **223-6349**, Monday-Friday between 8:00 a.m. and 4:30 p.m.

This license is **available only** from AG&F's Little Rock office. The Resident 3-Year Disability Licenses are **not available** by phone order or on-line.

# ASCC Web Site Puts On "A New Face"

The Arkansas Spinal Cord Commission (ASCC) has recently revised and updated its web site. The home page located at [www.accessarkansas.org/ascc](http://www.accessarkansas.org/ascc) now provides direct access to more than thirty areas of interest to visitors.

All members of the ASCC staff are listed, as well as their mailing addresses, phone numbers, e-mail addresses and office location and hours. The duties and current appointees of the Commission are easily found, along with a brief biographical sketch of each. Also the latest *Annual Report* and *Spinal Courier* newsletter are on-line as well as all (58) past issues of the newsletter.

Two new areas may be of particular interest to visitors. The first area, *Frequently Asked Questions*, provides answers to questions commonly asked by the public and clients about ASCC policy and services. The second area, *Upcoming Events*, lists the time and location of conferences, support groups, recreation, education and other opportunities for persons with spinal cord disability and their families.

These changes and others make the ASCC web site a more inviting place to visit. Check it out!

## ASCC Education & Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has all sorts of information on any kind of topic you could think of. The following are just a few of the wide variety of topics available to be explored:

Architectural Accessibility  
Education  
Employment  
Equipment  
Exercise  
Financial Issues  
Housing  
Personal Care  
Recreation  
Sexuality  
Travel

If you are interested in learning more about any of these topics or anything that's not listed above, call Judith at **296-1792** or **1-800-459-1517**.

### ADDRESS SERVICE REQUESTED

- ☐ Please remove my name from your mailing list  
☐ Please add my name to your mailing list  
☐ Change name or address as shown on address label

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